

The Silent Genomes Project

General Updates

Currently, we are in the process of building the IBVL. To prepare for sample transfer, the SGP team has prepared this newsletter to update communities about our governance and other aspects of the project since its beginning.

Overview of updates:

- Reviewed Terms of Reference of the S-GIRDD
- 15 S-GIRDD meetings over 19 months
- 2 Workshops
- Approved Data and Biological Material Transfer Agreement
- 12 Community visits
- 4 Annual meetings

Resources

- [S-GIRDD Terms of Reference](#)
- [IBVL Video](#)
- [The Silent Genomes Project Education Materials](#)
- [The Silent Genomes Project Best Practices](#)

Contact Info

- [Silent Genomes Project Website](#)
- 1 (888) 853-8924
- silentgenomes@uvic.ca
- [Twitter](#)

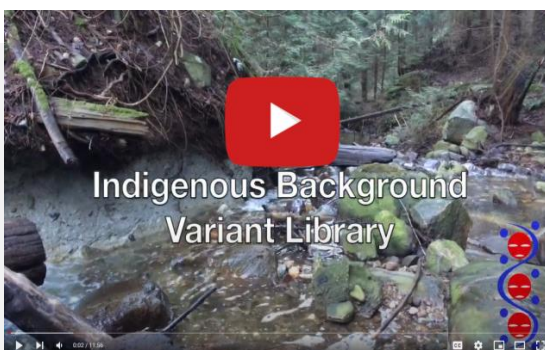
Background

The **Silent Genomes Project (SGP)** is a national research project that aims to improve diagnostic success for Indigenous Peoples with genetic diseases.

SGP includes four key activities:

- Activity 1: Integrating Indigenous-led governance, community engagement, community education, and student capacity building across all activities
- Activity 2: Precision Genomic Diagnosis for Indigenous Patients with Genetic Diseases
- Activity 3: Development of an Indigenous Background Variant Library
- Activity 4: Assessing the socio-economic impact of the IBVL and the Silent Genomes project in general

The Indigenous Background Variant Library (IBVL) is a reference dataset to help with the diagnosis of rare genetic diseases (for more information please see the video below). The IBVL will include 1) Samples from consented participants participating in the Canadian Alliance for Healthy Hearts and Minds (CAHHM) study and 2) Samples from consented participants from BC-based First Nations communities. Around 1,000 Indigenous samples are aimed to be collected for the IBVL. Samples coming from CAHHM are currently retained at their biobank at McMaster University but there will be no biobanking as part of the Silent Genomes Project.



Members of the activity 1 and 3 team in Victoria, BC. Pictured (from left to right): Irina Manokhina, Mohammed Abdallah, Wyeth Wasserman, Laurie Kariosta Montour, Laura Arbour, Solenne Correard, Brittany Hewitson, and Julia Hwang

Governance

The Silent Genomes Indigenous Rare Disease Diagnosis Steering Committee (S-GIRDD) comprises 8 to 12 Indigenous members, including Elders, community members, and representatives from national Indigenous organizations (see resources for the list of members and terms of references). The S-GIRDD Steering Committee was established to provide cultural oversight and strategic advice in support of the collaborative creation, implementation, and utilization of the IBVL including respectful, culturally safe policies regarding access to data and clinical diagnoses [and related research]. The Indigenous Governance Group which will succeed the S-GIRDD after the SGP is completed, is expected to be similar in composition to the S-GIRDD, but the final membership will be decided upon by the S-GIRDD prior to transition.

The S-GIRDD and the Indigenous Governance Group guides the development and the operations of the IBVL which includes

- Creating policies during the SGP and after the projects ends.
- Overseeing IBVL User approval and usage
- Ensuring the IBVL is culturally safe and accessible
- Providing input on security measures of the IBVL